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TRANSITIONAL SERVICES, TRAINING PROGRAMS, AND THE REALITIES OF DEVELOPING COMMUNITY-BASED SERVICES FOR MULTI-IMPAIRED BLIND AND DEAF-BLIND ADULTS

A

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HELEN KELLER SEMINAR

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KEVIN J. LESSARD

ASSISTANT DIRECTOR

PERKINS SCHOOL FOR THE BLIND

AMERICAN FOUNDATION FOR THE BLIND
15 WEST 16th STREET
NEW YORK, N.Y. 10011

The concept of developing Transitional Services for handicapped individuals in this country has been receiving more attention during this past year. Federal Grant monies have become available to develop model programs that focus on the development of these services and some schools and agencies serving multi-impaired blind and deaf-blind individuals have altered their training programs to focus their attention and efforts in either defining and/or developing needed community-based vocational, housing, and support services.

When one investigates the complexities involved with community-based vocational, housing, and support services and relates each area to the multi-impaired populations we work with, the problems become compounded. Most of us in the field of blindness are working with a significant number of blind individuals who have one or more additional impairments such as retardation, emotional problems, deafness, traumatic head injury, orthopedic involvement, and others. The presenting problems and inherent solutions to such a diverse population are truly complex when one attempts to design community-based services that will meet the needs of individuals from a housing, vocational and support services perspective. Yet, the population mandates that we as professionals become actively involved as developers and/or co-planners in the design and delivery of community-based services for such a diverse and complicated population. These are some emerging trends which alarm all of us in the field because they have serious and complicating implications when we analyze short term community-based service needs for multi-impaired blind and deaf-blind individuals.

We are all cognizant of the fact that a significant number of Rubella students will be turning age twenty-two (22) in the next few years. A majority of these students will have need for structured housing and vocational placements with a continuing need for an array of support and clinical services.

In addition there is an alarming increase in the number of young adults who suffer traumatic head injury as the result of an accident. Very few agencies serving the blind have begun to serve this population but the prevalence and advocacy surrounding this handicapping condition will alter some schools and agencies in the next few years.

The Rubella population, the Head Injured population, the number of multi-impaired blind individuals being deinstitutionalized, and community-based multi-impaired individuals will significantly increase the Adult population figures during the balance of the 1980's. Most importantly, the majority of the population will require comprehensive and on-going services for decades to come.

When analyzing the specific array of transitional services and training programs that are needed for multi-impaired blind and deaf-blind individuals one quickly comes to the conclusion that the scope of existing services will not meet the populations' needs.

In reality, the services and programs that will be needed for the population are not only transitional or short-term in nature but they are services and programs that will need to be long-term, including the very real possibility that a continuum will need to be developed that will attend to their life-long care needs.

The systems and services that need to be developed include transportation, housing options, recreation services, on-going training in independent living skills, respite care,emergency or supplemental financial assistance, architectural adaptations, Health Services, special equipment/adaptive devises, employment options or ongoing training, legal and advocacy services, counselling services, and volunteer services for such tasks as food shopping and food preparation.

In a 1983 survey completed by the Massachusetts Commission for the Blind entitled, "Planning Services for Persons With Severe and Multiple Disabilities" there was an identification of a lack of several support services which seriously affected their agency's ability to provide meaningful services to the multi-impaired. The three (3) most significant services which were lacking were transportation, supportive residential care, and preventive and follow-up services. Other areas that were identified as problems included the cost of services and equipment, the availability of information about services, poor intra-agency cooperation, and negative community attitudes.[1]

The functioning levels that multi-impaired blind and deaf-blind clients present can include a range of higher functioning individuals who can be integrated into competitive labor markets and independent living situations with minimal or no support services to those individuals who will require highly structured living arrangements and relatively intense support services, as well as structured and well defined day program services. The intent of this paper is to define categories of services that will be needed for such a wide functioning range of clients, with the full realization that Individual Service Plans (I.S.P.'s) for each client will require a thorough analysis and in some cases ongoing and comprehensive reviews before an adequate array of applicable and appropriate housing, support, and vocational services can be identified and developed for each client.

Madeline Will, Assistant Secretary for Special Education and Rehabilitation Services, states in an article entitled "Bridges From School to Working Life" that transition services can be grouped into three (3) classes. The first involves movement from school either without services or with only those that are available to the population at large. The second involves the use of time-limited services that are designed to lead to independent employment

at the termination of service, and the third involves the use of services for those individuals who need consistent and ongoing support.[2]

Professionals who work with multi-impaired blind and deaf-blind individuals are often perplexed when they attempt to design a continuum of services outside of the traditional education training or rehabilitation training programs that they operate. It is not always clear how to have a significant impact on the development of an array of long-term services that multi-impaired blind and deaf-blind need, and the task of developing an array of services can be overpowering.

"Accountability" is a concept that has been receiving a considerable amount of attention during the past few years. The term "accountability" permeates the literature in the fields of education, special education, business, politics, and many other areas. Knowing how to be accountable has never been well defined, and it is within this context that I would like to define our professional responsibility to students and clients we are presently serving in our public school, residential school, or rehabilitation programs: responsibilities that we have to students and clients while they are being educated or trained in our programs, and responsibilities we have as students and clients leave our programs and become integrated into the community.

The word accountable is defined as, "To be answerable and capable of being explained." Accountable further "emphasizes liability for something of value, either contractually or because of one's position of responsibility." This definition of accountability can and should have major impact on us, the professionals in the field of the education and rehabilitation of the blind and deaf-blind. It should govern our administrative and teaching philosophies, methodologies, and commitments to program development. Accountability should

never be something that deals solely with paper compliance or something that is interpreted as a concept that is simply "in vogue," creating additional pressures on all of us.

Accountability was, in essence, an easier concept to deal with and respond to just a few years ago. It has become more difficult with changing National, State, and Local cutbacks and philosophical shifts toward the handicapped. Perhaps if we had been more accountable and more responsive in the past, we might not find ourselves in the same fiscal and programmatic crises that we presently face.

Perhaps too, if we had spent more time attending to the development of accountable services within the spirit of Public Law 94-142, State Special Education Legislation, and Rehabilitation Legislation we would have easily accessible follow-up data in which we could prove the efficacy of our services. Now we find ourselves with either limited, or, in some cases, non-existent data, and trying to plead with legislators and funding agents at all levels with information that has less impact, and information that does not necessarily impress them from a fiscal, political, or tax-incentive standpoint.

The era we presently find ourselves in is truly a complex one. It is an era where programs can be dismantled quickly: an era that can potentially affect thousands of blind, visually impaired, and deaf-blind individuals now and in the forseeable future. It is an era when we as educators and rehabilitation personnel must begin to redefine our responsibilities and become more creative and responsive, in order to prove that our services will, in fact, have a direct and positive impact on the students and clients we serve. This will require a commitment beyond which we are accustomed, a commitment that will be one with no frills, a commitment that will demand us to identify

what skills individuals will need when they complete our educational and rehabilitation training programs, and a commitment to initiate and/or participate in the development of services in the community; services that will ensure humane, productive, and cost-effective housing, vocational, and recreational opportunities.

Within a truly accountable system it is critical that we as professionals address a number of significant issues, and even though times are more difficult than they were just a few years ago, as professionals we need to respond to the challenges and face a number of issues in a more constructive manner. In the areas of daily living skills, community experience programs, and vocational training, we have the major responsibility to create and provide comprehensive and reality-oriented training programs for the students and clients we serve. It is our responsibility to ensure that students and clients are adequately trained to meet the demands which will be expected of them in various living and vocational options available in the community. Furthermore, it is our responsibility to participate in the planning and development of living and vocational options in the community for multi-impaired blind, and deaf-blind individuals now and in the future. It is these three (3) concepts that must be incorporated into our definition and design of training programs.

Do our training programs attend to a comprehensive set of services which do, in fact, train multi-impaired blind and deaf-blind students and clients to meet the demands of living and vocational options available in the community? Do our training programs include active participation on our part in the planning and development of living and vocational options to be made available to these individuals in the future? If we as professionals cannot answer "yes" to both of these questions, the structure and delivery of our programs and the time and effort extended by staff and other professionals will not

be truly accountable to the students, clients, families, and agencies that we serve.

- How many multi-impaired blind, visually impaired, and deaf-blind adolescents and adults have the advantage of receiving a comprehensive, reality-based, and long-term oriented daily living skills community experience, or vocational training program?
- How many individuals have a clear, concise explanation of their rights and a strong supportive atmosphere to operate within our educational or rehabilitation systems?
- Do we have the skill to identify relevant and appropriate curricula and teaching methodologies for each individual we serve?
- Do we have systems that are interdisciplinary in nature in which clinical or diagnostic staff and instructional or teaching staff work closely and consistently with one another to determine the current functioning level of the individual and cooperatively plan both short- and long-term goals?
- Do we as professionals really think we share the same level of intensity and concern about the future as students/clients and their families?
- Are the educational or rehabilitation training programs we offer tied into the life-long care continuum of services?

In describing the structure of a comprehensive education or rehabilitation delivery system for multi-impaired blind and deaf-blind individuals I would like to address the magnitude of the problems by focusing on the following areas:

- <u>COMPREHENSIVE EDUCATION AND REHABILITATION TRAINING PROGRAM AND PLANNING SERVICES</u>
- <u>COMMUNITY HOUSING SERVICES</u>

- VOCATIONAL/WORK OPTIONS
- SUPPORT SERVICES IN THE COMMUNITY
- LONG TERM OR LIFE LONG CARE SYSTEMS/FINANCIAL CONCERNS/ESTATE AND TRUST PLANNING/FEDERAL AND STATE LEGISLATION AND FUNDING ISSUES
- SUMMARY AND RECOMMENDATIONS

The above seven (7) areas are inter-related and for most multi-impaired blind and deaf-blind individuals attention to most, if not all areas, is a necessity. My intent in dividing the areas into seven (7) is to identify and elaborate on the complexities involved in each, fully realizing that the inter-relationships are very real and without careful consideration of each variable, a comprehensive and effective plan cannot be developed for each client.

COMPREHENSIVE EDUCATION AND REHABILITATION TRAINING PROGRAMS AND PLANNING SERVICES

In designing a comprehensive training program for multi-impaired blind and deaf-blind individuals, the identification and/or creation of a developmental and all-encompassing curriculum is necessary. The curriculum must be stated in terms of behavioral objectives and should include task analysis and the development of specific criteria for meeting each of the objectives. The development of creative teaching strategies and innovative methodologies developed within the framework of interdisciplinary teams are also critical in the delivery of these services.

Within a school or agency treatment program, instructional staff, including teachers, residence staff, and teacher aides play the most significant role in the teaching of daily living skills, vocational training, and support skill areas. Responsibilities within these various job roles and job descriptions need to be clearly defined in conjunction with adequate pre-service and in-service training programs . Clinical Intervention from personnel such as psychologists, behavior

management specialists, social workers, occupational therapists, physical therapists, and speech pathologists, who provide either direct services or consultative services to instructional staff, is critical if interdisciplinary team services are to be realized.

Professional staff certified in the areas of daily living skills, rehabilitation teaching, and vocational training are critical in the development of in-services training programs. The expertise they bring to an educational or rehabilitational program needs to be coordinated for professional and paraprofessional staff who work with students and clients.

In order to effectively plan an individual service plan for each student or client during evaluation meetings, annual reviews, or case reviews, a coordinated and well-defined set of objectives must be determined. However, in addition to defining the developmental level of a particular individual and their short-term goals, it is vital that all staff be aware of which individual skills they are to teach, and what reinforcement strategies must be utilized. Duplication of efforts must be avoided as well as conflicting methodologies if multi-impaired individuals are to receive the greatest benefits from programming and be able to realize their maximum potential.

The skills that a student or client need to focus on include home and personal management skills such as budgeting, banking, purchasing, hygiene, and grooming. Health care is also critical, and for higher functioning individuals, trianing should include prenatal, infant and child care, the use of drugs and medicine, medical services in the community, and effective use of leisure time. A very heavy community experience program should be emphasized, and trips into the community should become a regular part of training experiences. All these skills, however, should not be taught just as an academic exercise in the training area. For example, lunch preparation should not take place at 8:30 in the morning and the training and handling of money should eventually lead the multi-impaired individual to the actual handling of cash transactions

in local supermarkets, post offices, or banks on a regular basis. This requires a training system that not only develops realistic curricula but provides in-service training, resources, and support to teachers so that their strategies and methodologies show a sensitivity and awareness of providing appropriate experiences to students and clients in the community rather than in a vacuum.

Diversified, yet applicable, self-contained apartment training needs to be incorporated into the program so that multi-impaired individuals are gradually allowed to prepare their own meals on a daily basis, are given more responsibility in self-help skills, and begin to gain experience in more semi-independent living conditions. Live-in programs which simulate staffed apartments or community residences require different staffing patterns, home-like physical facilities, and a well-defined instructional program which systematically identifies realistic, yet attainable, goals and expectations.

Daily Living Skills Programs and Vocational Training Services cannot be viewed just as separate entities, however, in that most courses or services an individual receives have direct applicability to these areas. Orientation and mobility training, motor training, physical education, and physical conditioning programs are all important components of a total life skills program for a multi-impaired blind or deaf-blind individual, and the applicability and importance of these services is well documented. Recreation services, social skills training, and the effective use of volunteer services must also be incorporated into a program for most of our students and clients. The skill development and attitudinal variables incorporated into prevocational and vocational training programs can have direct correlation with a daily living skills program. The language and communications program being offered to each individual either in the classroom or self-contained instructional area must be tied in closely with the overall goals and objectives of the daily living skills and vocational program.

All of these services, which comprise the majority of an individual's program, must be coordinated and well defined so that daily living skills and vocational training are not attended to in isolation, and reinforcement strategies are ensured.

Obviously, the extent of instruction offered to each student or client will vary according to his or her ability, but training programs need to be developed and followed through according to each individual's abilities and levels of readiness, with long-range goals in mind.

The overall scope of daily living skills, community experience, and vocational curricula is extensive when independent or supervised living in the community is the ultimate goal. For students and clients who only have the capacity to live or work in a more dependent or structured living option, it is critical that interdisciplinary team assessment and planning determine the target goals on a short and intermediate basis while attention to long range goals is also being considered. The intent is not to sterotype or predetermine eventual living or work situations for individuals, but rather, to realistically and developmentally plan in a professional and creative manner. If we do not provide these types of curricula and experiences for individuals before they terminate our educational and rehabilitational program, who will intervene and provide realistic adult services for them in the community ?

The scope of a training program as outlined is extensive. In order to effectively implement these services, there must be an administrative commitment to implement this program within the structural design of a school or agency. Time must not only be allocated but the service delivery needs to be designed within the context of an interdisciplinary team. Adequate pre-service and in-service training programs must be provided for all instructional and clinical staff.

The individual service plan for each student or client must be formulated

as a result of a comprehensive diagnostic evaluation. Specific functioning levels in verbal and non-verbal areas, based on direct observation as well as standardized test instruments for the population, can be used in conjunction with language development levels and other clinical assessments in areas such as occupational therapy.

It is critical that psychologists and other clinical staff, such as educational assessment specialists or learning disabilities specialists, have the ability and insight to translate the testing results for all staff who provide direct services to the student or client. Attention must be focused on the appropriate identification and development of realistic teaching strategies and teaching methodologies. Within a day or residential treatment setting, there is a need to create interdisciplinary teams where the supervisor of a program works closely with teachers, specialty instructors, teacher aides, and residence staff. They need to work as a team in the setting of common goals and objectives for each individual student or client. Clinical staff must also be part of this team and psychologists, social workers, physical therapists, speech pathologists, and occupational therapists ensure a comprehensive and consistent program for each multi-impaired individual. A psychologist or anyone else performing diagnostic assessments needs to translate the data rather than simply read test results so that teaching and residence staff feel comfortable participating in an open dialogue with them.

Additional expectations of the Clinical staff should include participation in all program activities and observation of students and clients in classrooms and residence or apartment settings. They should also be expected to work flexible hours rather than just the traditional 9:00 a.m. to 3:00 p.m. workday. They need to know demands and expectations made of students and clients at

breakfast and supper times, and how individuals use their leisure time in the evenings and on weekends. Clinical staff need to develop a level of communication with teachers and residence staff on a daily basis rather than being seen as someone who only tests the student or client, or someone who provides counseling once a week in isolation.

Appropriate and realistic diagnostic assessment is absolutely critical. However, the transferring of this information and the level of communication that exists between Clinical personnel and Instructional staff is just as critical. If either one of these two variables is not functioning, then the service delivery system will not be as comprehensive as it needs to be for the multi-impaired individuals we are serving.

Attention to specific orthopedic impairments and intervention strategies or prescribed adaptive devices require the expertise of physical therapists and occupational therapists. Providing in-service training and consultation to instructional staff can create an environment where interdisciplinary approaches can ensure consistent, safe, and productive programs for each individual.

Educators have traditionally been responsible for providing services to students from birth to twenty-two years of age. Rehabilitation personnel usually assume responsibility for handicapped individuals twenty-two years of age and older. Each group of professionals is usually governed by specific legal, financial, programmatic, and legislative guidelines. In reviewing the literature in the field of special education and, in particular, blind services, there is very little written about a cooperative and well-planned system of communication between these two major human service providers. The number of model programs or joint delivery systems cooperatively planned between educators and rehabilitation personnel are limited.

When we analyze the complexity of a wide functional range of multi-impaired individuals it becomes obvious that educators and rehabilitation personnel must begin to work together if an effective continuum of services is to be realized. How often have we seen educators and rehabilitation counselors being critical of each other? How often have we seen students/clients and their families caught in the middle? If the developmental process is understood by all, and the services a student or client is receiving attend to his or her specific needs, perhaps an open line of communication can be realized. The problems of the multi-impaired are many. Issues relating to social interaction with peers and other adults, psychological adjustments to their impairments, concerns regarding their future, unanswered questions about their own identity and present future medical needs are areas of concern for the multi-impaired individual and their families. As professionals it is our responsibility to provide appropriate and realistic services for each student and client with identifiable short, intermediate, and long-term goals being part of the training program. As professionals, it is our responsibility to communicate and work closely with other human service agencies, students/clients, and their families in the planning of services that are credible, obtainable, and realistic.

Educators need to seek the active involvement of rehabilitation personnel during the early adolescent years so that when regular case reviews, staffings, and annual plan meetings have convened, a multi-disciplinary team can be represented. Hopefully, this multi-disciplinary team can develop into an interdisciplinary team that will focus on short, intermediate, and long-term goals. What must be avoided are last minute crisis-oriented transfers of students from an education system to a rehabilitation network of services. The concept of transfers is a delicate one that has an impact on all individuals. Educators and rehabilitation personnel may need to consider a redefinition of

their roles as it relates to a level of involvement in the area of long term planning for multi-impaired blind and deaf-blind clients.

COMMUNITY HOUSING SERVICES

Developing housing services in the community for multi-impaired blind and deaf-blind individuals is an area that needs a great deal of attention. Some State Mental Health Systems in this country have had a long history of developing community-based housing services for their clients who are retarded or disturbed and there have been some examples where multi-impaired blind and deaf-blind individuals were integrated into their already existing programs. However, these examples are for the most part limited, and I have approached this section as a separate entity on the premise that professionals in the field of blindness will need to become much more actively involved in developing appropriate housing services in the community for the individuals they serve.

In some State Mental Health Systems there is a mandate, such as Massachusetts has to provide community based housing services to Court-Ordered Consent Degree Clients on a priority basis. This factor combined with the inappropriateness of placing multi-impaired blind and deaf-blind individuals in some of these residences mandates us to consider a separate effort under the Blindness System in most States. Joint planning may still be appropriate with Mental Health Systems in a particular State but the primary thrust will need to come from a Commission for the Blind in conjuntion with other State and private agencies.

In order to clarify and emphasize the considerable number of variables associated with the development of community-based housing services, I have divided this section into three parts. They are as follows:

- A General Structure of Living Options for Multi-Impaired Blind and Deaf-Blind Individuals.
- A description of the Housing options presently being developed or operated by Perkins School for the Blind.

- A number of issues that professionals in the field of blindness will encounter as they develop community-based housing services.

Living Options In the Community

There are a number of living options which have been developed in some communities during the past decade. If we analyze the range and scope of options, it can be viewed as a continuum and includes the following levels:

- Community Residence Living - Heavily Supervised - Intermediate Care Facility (ICF-MR)
- Community Residence Living - Moderately Supervised
- Living At Home With Parents or Siblings
- Supervised Apartment Living
- Staffed Apartments
- Living With Roommates
- Living Independently

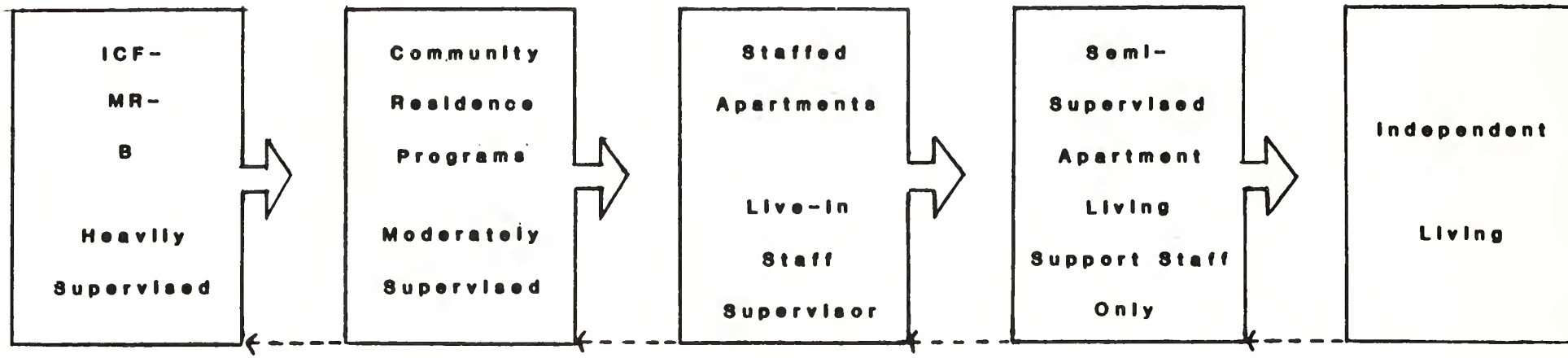
Chart A depicts the Continuum Of Semi-Independent and Independent Living Options which should be available to multi-impaired blind and deaf-blind individuals.

It remains to be seen whether or not the array of options is sufficient and/or adequate to meet the needs of a diverse population, but it certainly is a starting point from which we can build. It is critical that multiple options be made available, and that we take an active role in lobbying for the development, refinement, and adaptability of options for multi-impaired blind and deaf-blind individuals. We need to be aware that the development of curricula must focus primarily on the basic skills and entry criteria requirements which determine whether or not a person is eligible and ready to meet realistic and viable goals within a safe, secure, and consistent environment.

CHART A

PERKINS SCHOOL FOR THE BLIND

COMMUNITY RESIDENCE AND INDEPENDENT LIVING SERVICES
A CONTINUUM OF SUPERVISED AND SEMI-INDEPENDENT LIVING OPTIONS IN THE COMMUNITY



I'm sure there are a few professionals who would question the concept of developing appropriate curricula within an educational or rehabilitational setting. We need, however, to assure that curricula is developed which will focus not just on short-term goals, but on long-term, tangible expectations and possibilities. However, have we all, as a group of professionals made a commitment to the advocacy issues related to the development, refinement, and adaptability of living options for indviduals when they terminate or complete our training programs? To what extent have we followed through on our commitment? Has our commitment been sufficient?

These living options should be considered as a continuum for the present, with continued development and alterations being needed. It is our responsibility as professionals to maintain an awareness and consciousness relating to living options for mutli-impaired individuals. It is our responsibility to continue to initiate and advocate for the development of future living options that our different communities may develop. The issue of housing is such a critical problem because employment and/or additional training cannot be feasible unless adequate and appropriate community-based housing is available. Through the development of homemaker/health aide programs, a person's own family may also be considered an option on an intermittent basis if the psychological, social, medical, and day-to-day concerns can be attended to.

Most importantly our education and rehabilitation training programs must be designed and implemented in conjunction with the availability and understanding of actual community placements.

Housing Options Presently Being Developed By Perkins School for the Blind In Various Communities

This section is intended to outline and describe the present status of Perkins' Community Living Services Program off campus. It will also suggest strategies that will be developed during the next twelve (12) months. This section will also provide an outline of future directions that can be considered in relation to the expansion of these services with specific reference to funding sources, political advocacy groups, and related management issues for which Perkins will be directly responsible.

For the past two (2) years we have been directly involved in discussing the issue of appropriate housing services for a broad range of multi-impaired blind and deaf-blind individuals. We have identified a need to develop a comprehensive continuum of services to adequately serve a substantial number of individuals who have completed or who are about to complete their formal education or training at Perkins. Through formal and informal follow-up surveys of our "graduates" we have clearly seen that a number of students and clients are either unemployed or underemployed. The major cause of unemployment is not necessarily related to a lack of skill development or a lack of job opportunities; rather it is primarily due to a lack of appropriate, structured, and semi-structured living options in the community. In many cases, our "graduates" could have been placed in competitive employment or Day Activity Centers if adequate housing services were available in the community where the business or industry was located, or in a nearby community where adequate public transportation services were available.

Programmatically and philosophically we have, therefore, become very active in exploring ways to alleviate what is in reality a tremendous need for blind individuals in the state of Massachusetts and throughout the United States. Our primary concern is for students and clients who will complete

their formal education and training at Perkins in the near future. We have developed proposals with The Massachusetts Commission for the Blind, the Massachusetts Executive Office of Human Services, The Massachusetts Department of Mental Health, and The Watertown Housing Authority. We have also worked closely with the developers and architects assigned to the Arsenal Housing Development. The following sections define the present status of our efforts.

As of June, 1984 there are three (3) major projects which are part of our Community Living Services Program. They are as follows:

A. Massachusetts Chapter 689 Grant

- In conjunction with The Watertown Housing Authority and The Massachusetts Commission for the Blind, we applied for and received a Grant from the Massachusetts Office of Communities and Development to provide housing services for twenty-four (24) multi-impaired blind and deaf-blind clients. The Grant award was for $621,000.00. The Grant money was to be used solely for the construction or purchase and renovation of three (3) two (2) family houses in Watertown, Massachusetts. All three (3) facilities are owned by The Watertown Housing Authority and each house will serve eight (8) clients. Our responsibilities in this project up to this point, have included the development of the initial proposal which was submitted to the State, consulting with the architects assigned to the project (Johnson and Olney Associates), outlining programmatic variables and physical space needs with the officials from the Office of Communities and Development, and preliminary site selection visits.

  Once appropriate facilities were identified, we were involved in the development and design of detailed plans to insure that

each house meets the specific needs of the projected client population.

One house meets the Department of Mental Health (DMH) licensing standards for an Intermediate Care Facility For The Mentally Retarded (ICFMR-Type B). This is a highly structured and highly supervised facility designed to serve eight (8) DMH clients who are from the State of Massachusetts. The full cost of providing residential services to these clients will be the responsibility of The Massachusetts Commission for the Blind (MCB). The funding mechanism will solely be a contract between The Massachusetts Commission for the Blind and Perkins. The contract is for one (1) year and will be renewable on a year-to-year basis.

The second facility is designed for a moderately impaired blind retarded and deaf-blind population, and only the first floor will be made accessible for the orthopedically impaired. The funding which will be needed to pay for the operating costs for this Program will come from multiple funding sources. Funding sources which will be available to pay for all or part of each clients' per capita share include The Massachusetts Department of Mental Health, The Massachusetts Commission for the Blind, client's Supplemental Security Income (SSI) insurance companies contributions, and trust or estate plans designed for individual client by parents/legal guardian and others.

The third house has been designed to meet the needs of a population that needs minimal supervision. The facility will not be made accessible for the orthopedically impaired. Once again, the operating costs of the Program will need to be financially supported by multiple funding sources as mentioned in the previous paragraph.

B. Arsenal Housing Development

- In September, 1979 we began consulting with Gilbane Construction Company of Providence, Rhode Island and Arrowstreet Architects, Inc. of Cambridge, Massachusetts on a housing project being developed for the elderly and handicapped on the site of the Arsenal in Watertown, Massachusetts. Our efforts and initiative eventually led to the commitment of five (5) low income apartments being offered to Perkins for training and/or short and long term living arrangements for multi-impaired blind and deaf-blind individuals.

The apartment project which is a high quality development was occupied in the Summer of 1982. The financial and budgetary structure of these apartments is comparable to the multiple funding sources used with two of the Chapter 689 houses, however, clients are expected to pay 30% of their monthly income towards rent, heat, and a percent of their utility costs.

In that there is no live-in staff assigned to this housing option, clients assigned to an apartment must be independent enough to function with the assistance of a teacher who visits the apartments daily for two (2) or three (3) hours. The costs for this instructional service is the responsibility of the client and it usually averages about one hundred dollars per month.

C. Perkins-Owned Houses Off Campus

- At present, Perkins owns three (3) houses in the Watertown area which are being used for residential programming.

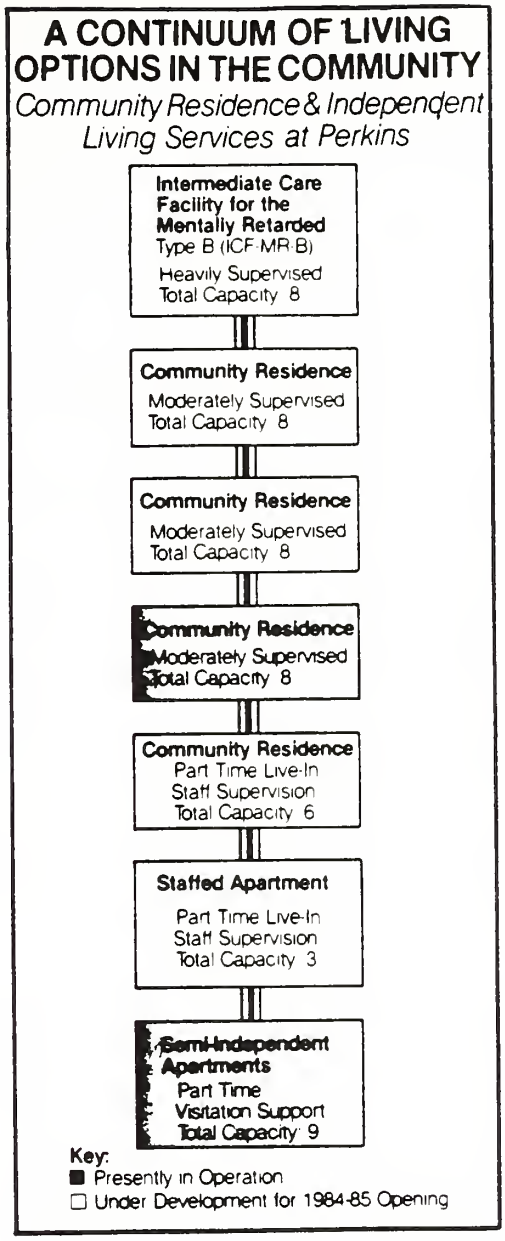
One house was purchased by Perkins during the Summer of 1981. It has been operated for the past eight (8) months as a staffed apartment. At present there are two (2) clients residing in the

house with one staff member. Both clients work and/or go to college part time, and they both pay a monthly rental fee to Perkins which includes all costs including the salary for the Residence Manager.

The facility is not accessible for the orthopedically impaired and it is not licensed as a community residence by the Dapartment of Mental Health. We are recommending that it continue to be used as a staffed apartment for higher functioning clients rather than being upgraded to meet licensing standards of the Department of Mental Health (DMH) for low functioning clients.

The other two (2) houses, however, have been leased to a neighboring agency for the past three (3) years. This agency received a substantial grant from a private foundation to renovate the facilities, and they have been licensed by the Department of Mental Health (DMH) and the Regional Review Board of Chapter 766. Just recently, both facilities have been vacated and returned to Perkins for off campus programming. Both facilities have been inspected to determine the amount of internal upgrading which is needed to make them ready for occupancy. Both houses can reasonably be used as community residences for multi-impaired blind and deaf-blind clients, and budgets are being developed for both Programs. One residence can accommodate eight (8) clients and the other one can accommodate six (6) to eight (8) individuals. Chart B outlines the potential number of clients which can be served in Perkins' Community Living Services Program during the first few years of operation.

Chart B



At this point, there are two (2) major issues which will be addressed in more detail in the near future. The first issue focuses on the area of estate and trust planning. In order for us to creatively explore, design, and develop proposals with parents/legal guardians and clients themselves we are formulating a position paper on the various options within the area of estate planning. This will include a concerted effort on the part of the Trustees, legal counsel, and administrative staff at Perkins to

to gather data and set parameters including the description of a range of options, and procedures to be followed in negotiations with parents/legal guardians and client advocates.

A second major variable that will be attended to and developed is the creation of a range of Day Activity Services. All clients residing in Perkins' Community Residence and Independent Living Services will be multi-impaired. It is anticipated that only a small percentage of them will be capable of competitive employment. Therefore, appropriate Day Activity Centers will be in high demand. In some cases it will be possible to integrate some of the multi-impaired blind or deaf-blind clients into already existing Day Activity Centers within a number of local communities; however, the majority of the clients will need to be served in a Day Activity Center designed and managed by Perkins. The major areas which Perkins is addressing and relating to Day Activity Centers include:

- Determine whether the responsibilities for the development of management of Day Activity Centers needs to be assigned to the Adult Services Program, Community Residence and Independent Living Services Program, or others.
- Decide if plans for Day Activity Centers should include provisions for both on and off campus facilities.
- Finalize licenses and/or Department of Labor Certifications needed to operate Day Activity Centers on and/or off campus.
- Develop staffing patterns and final budgets for such a program(s).

A Number of Issues That Professionals In The Field of Blindness Will Encounter As They Develop Community-Based Housing Services

At this point I would like to emphasize and explore in some detail various Real Estate and Housing Market concepts that professionals need to become familiar with if they are to take an active role in the development and/or advocating for community housing options.

- Valuation Analysis
- Initiation of Environments Clearance and Assignment
- Applicable Zoning Ordinances
- Location Analysis
- Appraisers Analysis
- Assigned Rents
- Marketability
- Preparations of Findings Memorandum
- Housing Management Analysis
- Economic Market Analysis

Hardly educational or rehabilitation jargon that we are familiar with in our day-to-day activities. Yet day-to-day jargon and concepts we must begin to become familiar with if we are to adequately prepare ourselves for becoming true advocates for multi-impaired blind and deaf-blind individuals whom we have been preparing for integration into the community.

The development of off campus housing services that have been designed at Perkins, have required our administrative staff to become more knowledgeable in areas not necessarily included in our undergraduate or graduate training programs. Our new contacts in the community become Lawyers, Real Estate Brokers, Local Housing Authority Personnel, Architects, and in some cases new and different Licensing and Accreditation agencies.

The process is an evolving one. It is at times frustrating and anxiety provoking. Better to be anxious on this level, however, than to deal with the anxiety and apprehension of not knowing what will happen to multi-impaired individuals that complete our education and rehabilitation training programs. Don't we have a deeper commitment to them than we have exhibited in the past? Hasn't our reluctance to implement comprehensive follow-up surveys of our graduates been a clear indicator that our efforts need to be increased substantially.

There is a deeper issue here than simply answering the proceeding two questions. The issue is one of a level of consciousness. I have often felt in the past that we as professionals have not attended to, "What really happens" to individuals who leave our programs? I suspect that our level of concern has been a questionable one at best. Perhaps we have tried to help out an individual student or client now and then, but our level of consciousness has never been one that has focused attention on each and every student or client.

This phenomena is nothing new to public or private education in this country. How many high schools, or colleges or universities concern themselves with the success of their graduates from a quantitative or qualitative standpoint? Yet as human service providers in this country; human service providers for a low incidence group of multi-impaired individuals, we have the responsiblity to be truly responsive to multi-impaired blind and deaf-blind individual needs. Needs that go far beyond what we offer them in the traditional context of educational or rehabilitation settings. We have the responsibility to initiate, create, and design, humane community environments for these individuals or at the very least, participate in the development of these services. It seems to me that as we create more accountable services in our programs, we will, in essence, force ourselves into the reality of services beyond our traditional offerings, and we will

develop more accountable services within community-based settings.

In designing an array of housing services for community residence and independent living service programs there are a number of issues that need to be addressed. The major topical areas are included on Chart C.

Chart C

- Funding Types
- Licensing Agents
- Real Estate Issues
- Facility Variables
- Liability Issues and Community Placements
- Staff Recruitment and Inservice Training Needs
- Administration of the Program
- Client Rights
- Client Services
- Estate and Trust Planning

Earlier in the section I was mentioning that professionals in the field of blindness were not necessarily well versed or knowledgeable in many areas affecting the development of housing services in the community. However, to look at the variables in Chart C in a more constructive manner, one can see that many of these topical areas pertain to the responsibilities included in an administrator's job description within a public school, residential school, or rehabilitation agency. There are obviously some key differences and there are also areas that require a significant amount of in-service training.

In looking at different funding types I have identified four or five ways to seek out monies for housing programs. At Perkins we are presently involved with three (3) specific types and there are others that may be available in the future. Through investigation and research, professionals can learn these systems quite quickly and realize that by using appropriate support which is available from professionals in the community, one's job can

be eased considerably.

Some types of funding for the development of community-based housing programs include, Federal HUD monies for the elderly and handicapped, State Chapter 689 funding, owning your own property, Section Eight (8) monies, and private monies.

Licensing agents responsible for overseeing the community residence and independent living options within local communities can include Departments of Mental Health, Public Health, and Public Welfare, as well as local building and fire inspectors. All of these agencies must be well coordinated, and staff that are supervising and operating community residence programs must insure that they have regular and open communication with a number of personnel working in these various agencies. A thorough knowledge of numerous regulations that at times overlap, duplicate, or are in conflict with one another is critical. In addition, a good degree of political savvy will help insure a smooth running operation.

There is a considerable amount of creativity which is needed to adequately raise money to finance the operational costs of community residence programs. The ICF-MR-B facilities are reimbursable through medicaid funds and it is critical that the responsible public agency within the State be identified. For all other residence programs the costs will obviously differ depending on the amount of supervision and staff intervention needed. The variance in costs can be significant for an array of services that range from highly structured to minimally supervised facilities. In the lower cost living apartments a blind individual would in most cases be able to support himself or herself on their wages and /or S.S.I. payments.

The more expensive programs will require a coordinated effort on the part of human service professionals, individual clients, funding agents,

parents/legal guardians, private funding sources, estates and trusts, insurance settlements, attorneys and others. An effective long-term financial plan for a client requires the efforts of many.

Given the significant number of lower functioning individuals who will require moderate to heavy staff supervision it might be wise to consider an increase in the number of Intermediate Care Facilities (ICF-MR) that are developed during the next five years.

Within the area of liability a knowledge of many issues concerning negligence are paramount and consultation with competent attorneys is a necessity. In developing a comprehensive system of housing services an administrator and his or her staff can attend to the wider array of liability issues, by defining from the outset a series of policies and procedures. Written policies can include admission and termination procedures, inspection procedures and a host of safety and security systems. In addition, emergency treatment plans, transportation safety in-service training and understandable record keeping systems are critical. A written behavior management or behavior intervention policy and appropriate in-service training is mandatory as are instruction in first aide training and cardio-pulmonary resuscitation (CPR).

This section has hopefully defined the complexities associated with development of housing services in the community and some ways of investigating the development of reasonable options. Specific issues relating to the funding of these services will be covered in a later section.

VOCATIONAL AND WORK OPTIONS

In a previous section, "Comprehensive Education and Rehabilitation Training and Planning Services" the context of interdisciplinary team planning for multi-impaired blind and deaf-blind indviduals was emphasized. In researching the present and future Vocational and Work Options for a multi-

impaired population it becomes clear, states Collins, "that recent studies done by Gold (1980), Bellamy (1980), and Brown (1978) have helped define a training technology which enables multi-impaired and severely impaired workers to perform complex job tasks. Wehman (1978), Rusch (1980) and others have demonstrated that multi-impaired and severely impaired individuals can be competively employed if they are appropriately trained and that this training involves much more than job task skills. Among the variety of skills that effect their employability that have been studied are topic repetitions (Rusch et al, 1980), time management (Connis, 1979); (Sowers, Rusch, Connis and Cummings, 1980) and appropriate responses to requests by supervisors (Rusch and Menchetti, 1981).

"The high unemployment rates of the multi-impaired and severely impaired attest to the continued need for vocational training programs and that competitive employment training is only one component of a comprehensive integrated community service delivery system. Among the other needed elements is long-term sheltered work (Williams, 1980).

"The movement of clients out of workshops into competitive employment and the emerging rehabilitation technology are effecting positive changes in the quality of training occurring at sheltered workshops. Attention to civil rights and legislative entitlements for medical services and income supports foreshadow additional changes at the community service level (Bellamy, Wilson, Adler, and Clark, 1980).

"However, even as sheltered programs improve, severely developmentally disabled individuals continue to be excluded from sheltered workshop programs. Surveys also show that the few who do participate in workshop programs are rarely incorporated into less restrictive enclaves within industry (Williams, 1980). In discussing recent sociological, educational, and behavioral, biomedical advances and their future implications for special needs populations, Lynch, Kernan and Stark (1982), identify

training techniques like video training, which could both expand the type of work that sheltered shops could perform and enable multi-impaired and severely impaired clients to greatly increase their skill level and production capacity.

"Dr. Lynch has elaborated further on that concept at a presentation at the AAMD Conference in Dallas (May, 1983). He predicts that American Corporations will subcontract assembly work to sheltered workshops instead of sending parts outside of the country to be assembled and then shipped back in order to save on labor costs. The American Corporations will then get quality workmanship and save on costs by taking advantage of the tax benefits, while the sheltered workshop will pay clients better wages and provide a more viable vocational option for the multi-imapired and severely impaired. This economic factor is perceived by some experts on sheltered work as a potential boom to the entire sheltered work industry." [3]

While many education and rehabilitation programs have further developed and enhanced their pre-vocational and vocational training programs for multi-impaired blind and deaf-blind individuals there remains a considerable amount of work ahead if an appropriate and reasonable continuum of vocational and work options in the community are to become operational and available to this low-incidence group.

In analyzing the vast range of functioning levels within the classifications of multi-impaired blind and deaf-blind clients it is clear that a range of placement options need to be developed due to fluctuating and diverse factors such as intellectual ability, behavior patterns, communication skills and abilities, orientation and mobility skills, and social and interactive abilities. Innovative model vocational programs have demonstrated that, aside from skill acquisition issues, frequently other work-related behaviors such as communication and interpersonal skills as well as behavior

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NEW YORK, N.Y. 10011

management issues are more serious obstacles to competitive job placements.

Project ADVANCE[4] was a federally funded Model Demonstration Program operated at Perkins School for the Blind and its primary thrust was to integrate deaf-blind students into structured and staff supported training programs in competitive work environments. The major project goals were based on the following hypotheses:

- Deaf-blind students can be more effectively trained for vocational skills and appropriate work-related behaviors within actual job sites rather than in simulated on-campus work environments;
- Deaf-blind students who will likely become sheltered workers can often times be better served through structured work within industry rather than in separate segregated workshop settings;
- Commercial tests and interest inventories used in isolation are of little predictive value for this population; a comprehensive vocational assessment can be developed and utilized via a combination of observational/situational evaluation tools and adaptation of commercially standardized tests;
- Vocational training augments, rather than detracts from, other educational training in terms of facilitating an increase in the student's self-esteem and motivation, improved mobility and communication skills, and the development of appropriate interpersonal skills and realistic expectations;
- It can be demonstrated that, with the provision of comprehensive training, support and follow-up, deaf-blind youth can engage productively and safely in a variety of work environments. This, in turn, can lead to raised expectations on the part of employers, advocates, rehabilitation professionals and parents as to viable vocational options for deaf-blind youth.
- It is cost effective in the long run to (a) utilize actual job sites as vocational training environments and (b) provide deaf-blind youth with a variety of community-based vocational experiences in preparation for several productive employment alternatives. In-

creasing the likelihood of future employment can lead to a partial or total reduction of S.S.I. and other benefits requiring public support by taxpayers and in turn allows deaf-blind individuals to become productive tax-contributing citizens.

Addendum A outlines in some detail the "Domains of Work Related Behaviors" that were incorporated into Project Advance and the components that are critical to successful training and placement for multi-impaired individuals. The "Domains" listed in short form are as follows:

Punctuality	Adaptability/Flexibility
Use of Time Clock	Communication/Socialization
Task Approach/Completion	Stamina
Attention Span	Appearance/Hygiene
Task/Skill Acquisition	Responsibility
Quality/Quantity of Work	Awareness/Practice of Safety
Acceptance of Supervision	Orientation/Mobility: Worksite
Response to Pressure	Orientation/Mobility: Work-Related Travel
Frustration Tolerance	

These factors require detailed and on-going attention if multi-impaired blind and deaf-blind individuals are to survive training programs and continue to function within a range of vocational and work options.

Chart D outlines a continuum of vocational and work options for multi-impaired blind and deaf-blind clients.

DOMAINS OF WORK-RELATED BEHAVIORS

A. Punctuality
B. Use of Time Clock
C. Task Approach/Completion
D. Attention Span
E. Task/Skill Acquisition
F. Quality/Quantity of Work
G. Acceptance of Supervision
H. Response to Pressure
I. Frustration Tolerance
J. Adaptability/Flexibility
K. Communication/Socialization
L. Stamina
M. Appearance/Hygiene
N. Responsibility
O. Awareness/Practice of Safety
P. Orientation/Mobility: Worksite
Q. Orientation/Mobility: Work-Related Travel

A. Punctuality

1. Arrives in work area on time.
2. Begins coffee break at appropriate/designated time.
3. Returns from coffee break on time.
4. Begins lunch break at appropriate/designated time.
5. Returns from lunch break on time.
6. Returns from restroom within appropriate time (10 mins.).
7. Leaves work area for toileting with appropriate frequency (less than 5 times per day).
8. Leaves work area at appropriate/designated time at end of day.

B. Use of Time Clock

1. Locates time card rack.
2. Selects own time card on rack.
3. Labels time card.
4. Locates time clock.
5. Punches in and out on time clock.
6. Punches in and out at designated intervals.

C. Task Approach/Completion

1. Goes to assigned work area and begins work immediately.
2. Locates necessary work supplies for job.
3. Sets up/stocks work area.
4. Interrupts work to attend to related needs (i.e., bathroom, drink of water, blowing nose, etc.).
5. Stops work and requests assistance at appropriate time.
6. Replenishes available work materials as needed.
7. Completes work in designated sequence.
8. Completes work within alloted time frame.
9. Continues working when supervisor is not present.
10. Cleans work area as needed.
11. Returns work materials to appropriate location(s).

D. Attention Span

1. Makes eye/tactile contact to task.
2. Daydreams (blank stare or lack of movement) less than 10 seconds during task.
3. Attends to task from initiation to completion.
4. Attends to task for up to:
   1 hour
   2 hours
   3 hours
   4 hours or more
5. Attends to task when sitting next to/opposite another.
6. Attends to task in large group setting (10 or more workers).
7. Remains on task while conversing with others
8. Remains on task during peer disturbance or environmental distractions.
9. Follows one-step commands related to task.
10. Follows two-step commands related to task.
11. Follows three- or more step commands related to task.

E. Task/Skill Acquisition

1. Learns to criterion new tasks of 1 - 5 steps within.
   15 minutes
   30 minutes
   1 hour
   1 - 6 hours
   6 hours or more
2. Learns to criterion new tasks of 6 - 10 steps within:
   15 minutes
   30 minutes
   1 hour
   1 - 6 hours
   6 hours or more

3. Learns to criterion new tasks of 10 - 20 steps within:
   15 minutes
   30 minutes
   1 hour
   1 - 6 hours
   6 hours or more
4. Exhibits retention of task by performing learned skills:
   at a later time in work day
   the following work day
   from week to week

F. Quality/Quantity of Work Produced

1. Completes 1 - 5 step task with:
   100% accuracy rate
   90 - 99% accuracy rate
   80 - 89% accuracy rate
   70 - 79% accuracy rate
2. Completes 6 - 10 step task with:
   100% accuracy rate
   90 - 99% accuracy rate
   80 - 89% accuracy rate
   70 - 79% accuracy rate
3. Completes 10 - 20 step task with:
   100% accuracy rate
   90 - 99% accuracy rate
   80 - 89% accuracy rate
   70 - 79% accuracy rate
4. Completes 1 - 5 step task at:
   90 - 100% of the competitive rate
   75 - 90% of the competitive rate
   50 - 75% of the competitive rate
   25 - 50% of the competitive rate
5. Completes 6 - 10 step task at:
   90 - 100% of the competitive rate
   75 - 90% of the competitive rate
   50 - 75% of the competitive rate
   25 - 50% of the competitive rate
6. Completes 10 - 20 step task at:
   90 - 100% of the competitive rate
   75 - 90% of the competitive rate
   50 - 75% of the competitive rate
   25 - 50% of the competitive rate

G. Acceptance of Supervision

1. Responds appropriately to requests for change in task.
2. Responds appropriately to requests for change in work location.
3. Responds appropriately to requests for change in work routine/sequence.
4. Follows rules/regulations in work area.
5. Responds appropriately to requests for quiet/calm.
6. Assists others when requested by supervisor.
7. Responds appropriately to requests for error correction, i.e., corrects errors willingly.
8. Responds appropriately to constructive criticism, i.e., attempts to implement change.
9. Stops/starts work when requested by supervisor.

H. Response to Pressure

1. Attempts to increase production upon supervisor's requests.
2. Attempts to increase production upon team's request.
3. Attempts to complete task by specific time upon supervisor's request.
4. Continues to maintain productivity after corrected for error(s).
5. Continues to work when being observed directly and at close proximity.

I. Frustration Tolerance

1. Maintains production on highly repetitive task.
2. Maintains production on less preferred task.
3. Exhibits calm and continues to work when co-worker has preferred task.
4. Remains calm and continues to work on challenging/difficult task.
5. Seeks assistance after several unsuccessful attempts.
6. Remains calm/seeks assistance when provoked by co-worker.
7. Waits appropriately during delays in team tasks.
8. Waits appropriately during work delay/stoppage.

J. Adaptability/Flexibility

1. Accepts changes in tasks from day to day.
2. Accepts changes in work locations from day to day.
3. Accepts changes in tasks during same day.
4. Accepts changes in work locations during same day.
5. Accepts time changes in daily schedule or routine.
6. Accepts supervision from more than one supervisor.
7. Continues to perform task following change(s) in instruction.
8. Continues to perform task following change(s) in co-workers' location.
9. Transfers/applies previously learned skills to new tasks requiring same skills.
10. Attempts alternative methods to complete a task when experiencing repeated difficlty.

11. Attempts alternative mode(s) of communication when not understood by others.
12. Tolerates alternative mode(s) of communication.

K. Communication/Socialization

1. Responds to requests or cues from supervisor.
2. Responds to requests or cues from co-workers.
3. Limits extraneous sounds.
4. Refrains from continual muttering or talking to self.
5. Limits extraneous movements.
6. Sits or moves about quietly when appropriate.
7. Initiates contact with others to seek assistance or make needs known.
8. Reciprocates/responds appropriately to greetings of others.
9. Initiates greetings upon entry/exit.
10. Displays friendly facial expression when interacting with others
11. Displays courtesy when interacting with others.
12. Socializes or engages in conversation during break time in a non-disruptive manner.
13. Socializes or engages in conversation during work time in a non-disruptive manner.
14. Refrains from use of obscene or vulgar language.
15. Refrains from flirtation or excessive physical contact with others.
16. Sits or bends in socially acceptable manner.
17. Initiates conversation with others during break/lunch.
18. Chooses topics of conversation which are appropriate to work setting.
19. Limits perseveration on topics of conversation.
20. Uses alternative mode(s) of communication when necessary.
21. Assists others (i.e., opens doors, carries objects, etc.).
22. Willingly shares with others.
23. Compromises to resolve conflicts.

L. Stamina

1. Sits at work station or in work area and remains on task (with scheduled breaks) for up to:
   2 hours
   3 hours
   4 hours or more
   full day
2. Stands at work station or in work area and remains on task (with scheduled breaks) for up to:
   2 hours
   3 hours
   4 hours or more
   full day
3. Performs repetitive physical work (with scheduled breaks) for up to:
   1 hour
   2 hours
   3 hours
   4 hours or more
   full day
4. Lifts work materials weighing up to:
   5 pounds
   10 pounds
   20 pounds
   30 pounds
   40 pounds or more
5. Maintains consistent quantity of work throughout work day.
6. Maintains consistent quality of work throughout work day.
7. Maintains productivity when working overtime.

M. Appearance/Hygiene

1. Wears appropriate outer clothing for varying weather conditions.
2. Dresses appropriately for work setting.
3. Wears clothing which is clean/pressed, coordinated and in good repair.
4. Wears footwear in good repair appropriate to work setting.
5. Maintains clean, neat hair.
6. Showers/bathes as often as needed to maintain cleanliness.
7. Keeps nails clean, trimmed.
8. Brushes teeth regularly.
9. Maintains clean-shaven appearance or neatly trimmed facial hair.
10. Maintains overall neat appearance throughout work day, i.e., adjusts clothing, combs hair and washes hands as needed.
11. Washes hands if appropriate, i.e., food or health services, before beginning work.
12. Washes hands after toileting, before returning to work.
13. Covers mouth when coughing.
14. Shields sneezes from work materials and co-workers.
15. Uses handkerchief or facial tissues when necessary.
16. Attends to feminine hygiene needs.
17. Exhibits good posture.

N. Responsibility

1. Seeks assistance to notify employer when sick/late.
2. Requests time off within appropriate time period.

3. Meets employer requirements for attendance.
4. Meets employer requirements for punctuality.
5. Follows through on supervisor requests or assigned tasks.
6. Accepts established standards of quality as criteria for employment.
7. Accepts responsibility for errors.
8. Apologizes when appropriate for errors.
9. Places personal belongings in designated areas.
10. Returns borrowed property in good condition.
11. Returns borrowed property within reasonable period of time.
12. Accurately reports experiences/events.
13. Accurately reports quantity of work.
14. When necessary, informs supervisor/co-worker upon leaving work area.
15. Cleans work area upon completion of task.

O. Awareness/Practice of Safety

1. Uses appropriate entrances and exits.
2. Walks (i.e., avoids running) from place to place in the work area.
3. Walks without bumping others.
4. Exhibits appropriate mobility techniques within work environment (i.e., stairs, low ceiling, etc.).
5. Identifies and avoids designated dangerous/restricted areas.
6. Wears protective clothing specific to task (i.e., goggles, gloves, hair net, etc.).
7. Adjusts hearing aids when noise level is detrimental to hearing.
8. Carries utensils/tools (i.e., knives, scissors, screwdrivers, etc.) in a safe manner.
9. Follows safety procedures when using utensils/tools.
10. Stores utensils/tools in a safe manner.
11. Cleans spills immediately after they occur.
12. Employs proper techniques when lifting work materials.
13. Stores materials in proper container or place.
14. Disposes of waste materials in appropriate receptacle.
15. Observes safety precautions specific to the use of machinery/appliances.
16. Holds plug when inserting into or removing from outlet.
17. Turns machinery/appliances off when finished.
18. Turns machinery/appliances off when cleaning.
19. Calls for help/notifies others during emergencies.
20. Accepts sighted guide upon being informed of emergency/evacuation.
21. Follows designated evacuation route during emergency/fire drills.
22. Follows alternate evacuation route during emergency/fire drills when primary route is blocked.
23. Avoids elevators/escalators during fire drills.

P. Orientation/Mobility: Work Site

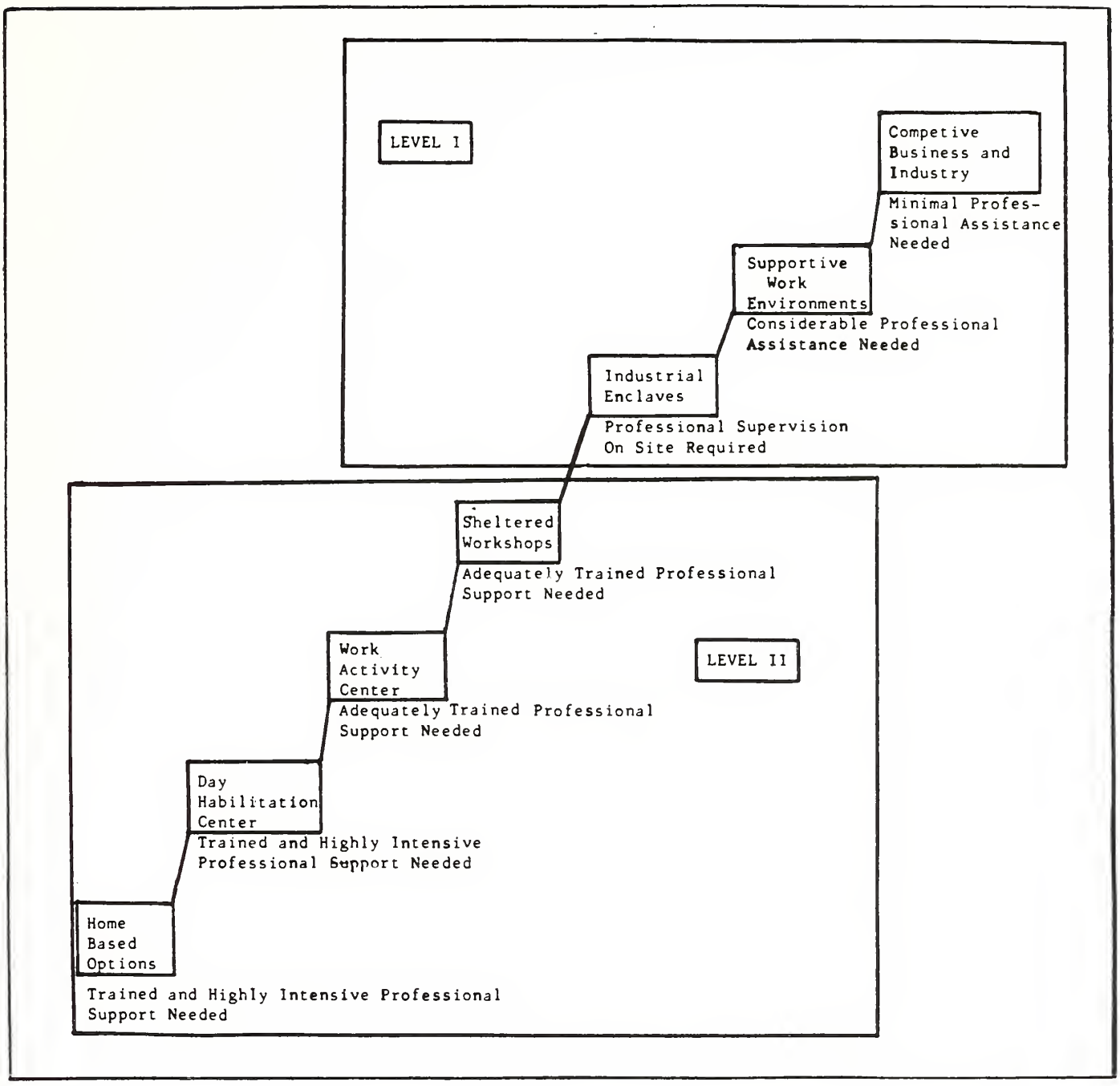
1. Locates appropriate room/closet/locker for outerwear and personal belongings.
2. Locates time clock area.
3. Locates sex-appropriate restroom.
4. When given work assignment, proceeds to appropriate work area.
5. Locates appropriate work station/table.
6. Locates seat.
7. Locates necessary work materials.
8. Arranges work materials in efficient manner or designated order to facilitate productivity.
9. Locates water fountain.
10. Locates coffee break area.
11. Locates lunch area.
12. Locates lunch table.
13. Locates necessary lunch materials.
14. Locates vending machines.
15. Walks from one work area to another.
16. Locates supervisor's office.

Q. Orientation/Mobility: Work-Related Travel

1. Carries or uses white cane in transit.
2. Walks to designated transportation point.
3. Walks to work site from residence.
4. Walks to designated bus stop.
5. Awaits arrival of bus at designated area.
6. Recognizes correct bus.
7. Waits turn when boarding bus.
8. Displays mass transit identification card when requested by driver.
9. Deposits correct change/token in fare box.
10. Seats self or stands with support of pole/handrail.
11. Uses landmarks or other cues to identify general area for disembarking.
12. Locates destination point.
13. Notifies driver of destination point or prepares to disembark by walking to front of bus.
14. Disembarks at destination point.
15. Elicits help when necessary to cross busy intersection.
16. Walks to work site from bus stop.
17. Follows designated procedure upon missing bus stop.
18. Follows designated procedure when bus service is temporarily halted.

CHART D

Continuum Of Work Options



On Chart D Level I options include Industrial Enclaves, Supportive Work Environments, and Competitive Opportunities in Business and Industry and these three options have been included in the same level due to the supervisory, administrative, and instructional/support staff variables associated with Federal and State Wage and Hour regulations, as well as community-based

contacts that need to be made in various business and industries. Obviously, researching the availability of training and/or job placements within the community requires an innovative, resourceful, and knowledgeable staff who are familiar with occupations for which there will be consistent and viable job markets now and in the future. Staff need to familiarize themselves with numerous resources which provide information about the current labor market and predict future employment trends.

Some of these resources can include:

- The Dictionary of Occupational Titles which includes information on descriptions of over 20,000 jobs in the United States.
- The Occupational Outlook Handbook which provides information on 250 occupational groups such as job duties, job outlook, earnings, and others.
- The Occupational Outlook Quarterly which updates occupational information and future employment trends.
- The Employment and Earnings Report which defines current industry data and statistics on the characteristics of the labor force.
- Individual State Employment Agency reports which provide analysis of labor market characteristics.
- Employer surveys which can be requested from various businesses and industries.
- A new publication entitled "A Manual of DOT Related Codes" by Karl F. Botterbusch, Ph.D. is helpful as a convenient listing of job related codes.

The list of basic skill jobs that would be appropriate for multi-impaired blind and deaf-blind individuals functioning in Level I are many and are too numerous to mention. However, there are some generic occupational areas which have been identified by The Occupational Rehabilitation Group[5] of Cambridge, Massachusetts and they are as follows:

- Medical Services
- Government Agencies
- Hotels
- Social Service Agencies
- Social Clubs
- Colleges and Universities
- Churches
- Restaurants
- Nursing Homes
- Day Care Centers
- Industry

This list is not intended to be all inclusive but it does list the major areas which would match the multi-impaired blind and deaf-blind clients' functioning levels and the research data on jobs which are presently available and those where there is a predicatable future employment trend.

Once a client's functioning level, skill acquisition level, interest, and readiness are determined there are a number of steps involved in identifying and securing an appropriate training and/or work placement in the community.

Staff from a client's training program and/or the client's rehabilitation counsellor must identify potential employers in the community and request an on-site visit to evaluate the employer's willingness to cooperate in identifying appropriate jobs.

An attractive option that can be explored with prospective employers is the Targeted Jobs Tax Credit Program (TJTC). The Projects With Industry "Forum" Newsletter states the following:

> "Hiring disabled candidates may mean more for business than hiring qualified workers. It may mean considerable savings on federal income taxes. The 1978 Targeted Jobs Tax Credit Program (TJTC) established tax credits for hiring persons who belong to "targeted" groups, among them handicapped persons who are enrolled in or have completed vocational rehabilitation programs.
>
> "The Program involves a minimum of paperwork and is easy to administer. There are three steps to follow:
>
> 1. The Job Service issues a voucher to the individual being

considered for the job, stating they are a member of a "targeted" group.

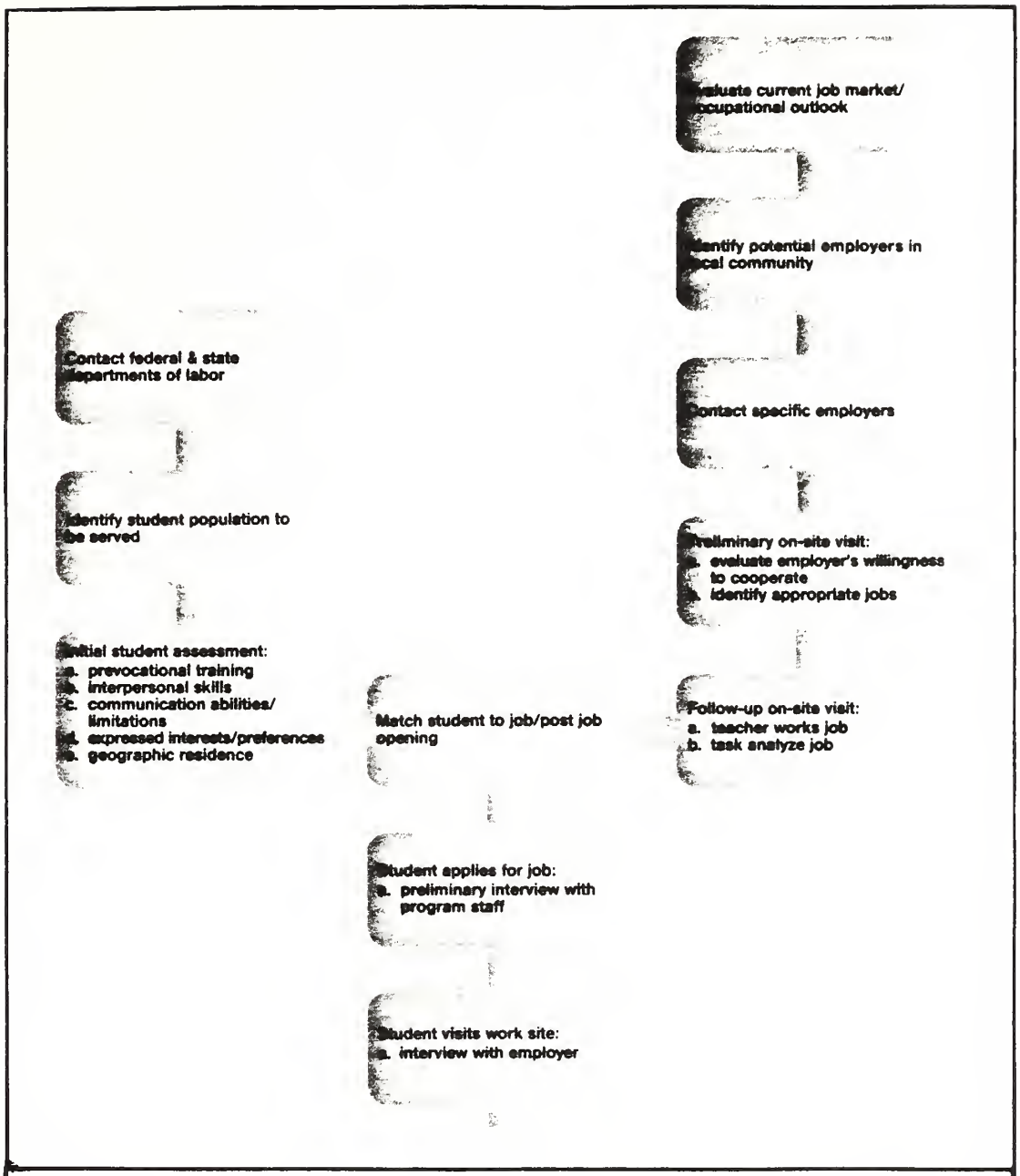
2. If the person is hired, the employer completes five items on the voucher, signs it and mails it to the Job Service office.
3. The Job Service sends an Employer Certification which is retained by the employer for claiming the tax credit.

"Tax credits are available during the first two years the employee is on the job. In the initial year, the gross tax credit is 50 percent of wages paid up to a maximum of $6000 (a $3000 credit). The following year the credit is 25 percent of wages paid to a maximum of $6000 (a $1500 credit). Actual savings depend upon tax bracket and are greatest for businesses in lower brackets. There is no maximum number of credits that may be claimed, however, the total tax credit is limited to 90 percent of tax liability.

"Individuals referred through PWI programs often meet the criteria established for businesses to claim the TJTC credit. More information is available on TJTC through Job Service Offices nationwide."[6]

If the employer is willing to cooperate with the client's contact person then an interview process can be set in motion. The following chart (Chart E) outlines the steps in this process.

CHART E



Project ADVANCE - Perkins School for the Blind
"Advancements: An Implementation
Guide To A Community-Based Vocational
Training Program For Deaf-Blind Youth", 1983

Once a position has been secured for a multi-impaired blind or deaf-blind individual it is critical that a network of services be set in motion to ensure a successful transition for the client during his or her training phase. It is particularly important that staff providing these transitional services be sensitive to the levels of apprehension on the part of the employer and co-workers. Sensitive and responsive in-service training for these people can help allieviate their anxiety if they are having difficulty with the accessibility issues relating to an orthopedically impaired client, or other adjustment issues that multi-impaired blind and deaf-blind clients present to the general public.

Regular and consistent communication with the employer is important before a teacher can feel free to begin to fade from the worksite.

Chart F outlines the steps that need to be taken during this Phase. It should be noted that there are phases on the Chart which pertain to students or clients that are still involved in an education or training program.

CHART F

Evaluate current job market/ occupational outlook

Identify potential employers in local community

Contact federal & state departments of labor

Contact specific employers

Identify student population to be served

Preliminary on-site visit:
a. evaluate employer's willingness to cooperate
b. identify appropriate jobs

Initial student assessment:
a. prevocational training
b. interpersonal skills
c. communication abilities/ limitations
d. expressed interests/preferences
e. geographic residence

Match student to job/post job opening

Follow-up on-site visit:
a. teacher works job
b. task analyze job

Student applies for job:
a. preliminary interview with program staff

Student visits work site:
a. interview with employer

Project ADVANCE - Perkins School for the Blind
"Advancements: An Implementation
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Training Program For Deaf-Blind Youth," 1983

For many multi-impaired blind and deaf-blind clients capable of Level I vocational and workplacements, the process will involve varying degrees of continuing supervision and monitoring. This monitoring should also include periodic updates on their total Individual Service Plan (ISP) including their present living arrangement and their present and future needs for community-based support services. The costs associated with this monitoring can be minimal or extensive depending upon their functional level and/or particular needs. The issue of funding for on-going support services of this nature are of growing concern and these issues will be elaborated upon in the section that focuses on financial issues.

Level II services listed on Chart D include Sheltered Workshops, Work Activity Centers, Day Habilitation Care Centers, and Home Based Options. These services are grouped together for obvious reasons and these services are applicable to a large number of multi-impaired blind and deaf-blind clients. Many multi-impaired blind and deaf-blind individuals will have significant difficulty with industry-based employment option due to serious intellectual, behavioral, communication, mobility, and social deficits.

For these clients it is critical that Sheltered Workshops or Work Activity Center training be considered one option. This will require a significant amount of work on the part of professionals to insure that Workshop personnel better understand a client's sensory deficits as well as other complicating conditions. When a deaf-blind client, is being considered for placement an emphasis needs to be placed on developing communication systems for the workshop personnel and co-workers. For other clients there may be additonal problems such as insufficient staffing ratios in the workshop and problems with the transfer of skills from one setting to another.

The following factors should be analyzed in assessing the appropriateness of a particular Shelterd Workshop for an individual client:

- Management attitudes toward multi-impaired blind and deaf-blind clients.
- Facility staffing ratios.
- Compatibility of the present client base in the Workshop.
- The types of work contracts in the Workshop.
- The variability in work assignments for clients.
- The emphasis on productivity.
- The length of a typical work day.
- Other support services which may be offered.
- Transportation factors in relation to the living option.

For lower functioning clients integration into already existing or to be developed Day Habilitation Programs will be the most reasonable option. For many multi-impaired blind and deaf-blind adults, however, there is a tremendous need to develop model programs that will specifically address their needs.

The content of the model states Collins: "must incorporate the educational, prevocational, daily living skills, medical and recreational aspects of programming which the population will require."[7]

The educational focus of the program must identify activities that will enhance the clients' concepts and language. The prevocational component should emphasize these training activities which will continue to prepare clients for eventual vocational placement in shelterd work options. The daily living skills, medical, and recreation focus of the program must be designed to maximize the client's potential in order to insure his or her placement in a community-based housing option.

For clients who are in need of home-based day services due to significant medical and/or other handicapping conditions or due to limited or unavailable

community-based services the problems can be significant. For a multi-impaired blind or deaf-blind client who has need for a supervised home or apartment setting and who also has an only option of home-based services the costs can be prohibitive, whereas a client who needs limited or minimal supervision will incur significantly less cost. The costs associated with Day Habititation Services will not, in most cases, be affordable for the majority of clients, and it will be necessary for various human service agencies to fully support or cost-share expenses related to these services,

In the final summary of the Project ADVANCE report it states that,

"The development and implementation of a community-based vocational training program places large demands on both educational staff and students in terms of time, energy, sensitivity and flexibility in an ever-changing job market. Yet despite the initial investment of such a program, there are clearly many long-term benefits.

"The deaf-blind students participating in Project ADVANCE have had the opportunity to be integrated with non-disabled co-workers in actual job settings where work demands are realistic and role models are more readily available. On-the-job training has provided these students with a first-hand chance to experience and learn the subtleties of appropriate social and work behaviors, as well as specific occupational skills.

"The data provided by the Project ADVANCE research study indicates that given proper vocational training, follow-up and support, deaf-blind students can improve their independent performance of work-related tasks, their ability to communicate with employers and co-workers, and increase their productivity. In addition, these students were able to diminish inappropriate behaviors which may have interfered with employability while experiencing increased feelings of self-worth and expectations for semi- to independent functioning.

"Project ADVANCE is demonstrating that there are many more viable work alternatives for the deaf-blind individual than had

previously been thought. It is imperative that we make this early investment in the vocational education and training of the deaf-blind adolescent to provide him/her with those skills which will increase the likelihood for the least restrictive type of vocational placement and will facilitate successful transition to the world of work."[8]

Vocational training and vocational work options are critical components of a client's overall community-based program. Clients will not be admitted or allowed to continue in most Group homes and/or semi-independent apartment settings unless they are gainfully employed in a competitive job or day activity program and out of the residence Monday through Friday from 8:30 a.m. to approximately 4:00 p.m.

The development of a client's Individual Service Plan must incorporate and include a vocational or work option if comprehensive community-based services are to be realized for each individual.

SUPPORT SERVICES IN THE COMMUNITY FOR MULTI-IMPAIRED AND DEAF-BLIND INDIVIDUALS

In addition to the service delivery and cost-factors raised in the Housing and Vocational sections of this paper it is important to analyze the complexities and funding variables associated with related support services for multi-impaired blind and deaf-blind individuals in the community.

The following variables will be discussed in this section:

- Transportation Needs
- Leisure Services
- Respite Care Needs
- Emergency Financial Assistance
- Health Counselling and Other Therapeutic Services
- Legal Advocacy
- Volunteer Services
- Architectural Adaptations/ Specialized Equipment/ Adaptive Devices

- Transportation Needs - In a majority of cases it is clear that multi-

impaired blind and deaf-blind individuals will need to have transportation services in order to get to and from work and in order to participate in the use of community resources. The costs will vary depending on the location of the living option in relation to all other activities. As much as we might like to plan all factors of a client's program needs, it is clear that multiple variables and split or separate funding sources do have limitations. Therefore, transporation costs can be a significant effect on the overall financial plan for each client.

In an ICF-MR-B transportation costs are incorporated into the operating budget and this allows for the staff costs, rental, and operating costs of a van that can transport clients to and from work community experiences, and other needed program destinations. However, in other community residence and semi-independent or staffed apartment living arrangements transportation costs must be built into the operating costs of the facilities and these costs must be assumed by the client who is already facing significant costs in other areas. In addition, if there are six to eight clients living in one facility this can create additional administrative problems in arranging and coordinating transportation for multiple trips, five to seven days per week.

Local transportation systems such as private or State-oparated transit authorities may offer services to handicapped individuals for a nominal fee and even though scheduling may be difficult and cumbersome at times, it does offer some needed respite in certain States. It is far from being a panacea for handicapped individuals and transportation outside of Medicaid eligible facilities such as an ICF-MR-B will continue to be a significant and costly item for multi-impaired blind and deaf-blind individuals.

- Recreation Services - In addition to the leisure time activities that are provided to a client who is living in a structured living arrange-

ment it is critical that community-based recreation services be explored in some detail. Depending on the individual's functioning level an array of options should be explored by the client in conjunction with the direct care and/or support staff. Once again, transportation and its related costs need to be analyzed, as do the general costs associated with the recreational interests of an individual client or small or large groups.

Communities differ significantly in the range of recreational options that they offer and with recent tax limiting legislation in some cities and towns the number of low cost community supported activities has decreased. It is important for support staff to research low cost options in their own town or surrounding communities and help advise clients of reasonable financial/ transportation opportunities which are available. The securing of an adequate number of volunteers can help in this process.

- Respite Care Needs - For lower functioning multi-impaired blind and deaf-blind clients the issue of respite care continues to be a problem and concern. No matter what the living arrangements may be there are times during the year when respite care arrangements can be in the best interest of the client, residence staff, and the clients' family. This is obviously an individual matter, but even in heavily populated areas where respite services may be available it may once again become a financial issue. For some multi-impaired blind and deaf-blind clients it may also be an additional issue with respite care providers who, because of the low incidence nature of the the population, may feel uncomfortable working with the handicapping condition(s). Continued efforts are needed in developing a continuum of respite care options for some multi-impaired blind and deaf-blind clients, and in some respects the identification of such options may be the only way certain clients will be able to remain in community-based services.

- Emergency Financial Assistance - A client is living in a Community

Residence or Staffed Apartment and is doing quite well programmatically, he or she has somehow survived financially difficult times for a year or two. Suddenly, there is a shortfall on the present month's payment to the agency that is operating the facility that the client is living in. The reasons could be many, a reduction in S.S.I. Benefits, an outstanding bill that has come due or an unexpected expense. What does a client do? What does the sponsoring or operating agency do?

There needs to be some form of emergency financial assistance which can adequately yet fairly be monitored in such situations. In most cases the particular emergency may be explainable and justifiable, yet without adequate resources the community-based arrangements for an individual client can be jeopardized and/or terminated.

- Architectural Adaptations/Specialized Equipment/Adaptive Devices Given the handicapping conditions that are possible with a multi-impaired blind or deaf-blind individual it is imperative that architectural adaptations/ specialized equipment or adapative devices and the funding availability for such adaptions or equipment be fully explored by the sponsoring agency and/ or the administrative staff of the responsible human service agency. Through exploration of Federal, State and local or private resources it might be possible to identify a funding source which could alter the environment and/or make the living or work situation more accessible and safe for the multi-impaired blind or deaf-blind individual. In some State Commissions for the Blind there is an Engineering Specialist who can be of assistance in both designing adaptive devices and in identifying specialized equipment and in the identification of a federal, state, local or private funding source. If this is not possible the costs of the adaptation or equipment may have to be assumed by the client.

- Health Services - For many multi-impaired blind and deaf-blind students the identification of appropriate and comprehensive health services within

within various communities is essential. In fact, the specific geographic location and placement in a group home, staffed apartment, or other living option should be dependent on the availability of needed health services for an individual.

Most clients will be eligible for Medicaid Health Insurance within their respective State and in many cases this coverage will include counselling and other therapeutic services such as physical, occupational and speech therapy. For some client/individual health plans may be available from their part time and/or full time jobs. It is incumbent for the residential staff or case management personnel to work closely with each client to adequately research and explore local health and therapeutic services such as those offered by local health centers, hospitals, or clinics.

Legal and Advocacy Services

The availability of legal services for disabled individuals may be found through a local or regional developmental disabilities law center. It is here where trained attorneys in areas of handicapped legislation can offer counsel and/or assistance when a client has need for legal intervention. Costs for such services may be minimal or based on a sliding scale, so that the financial implications for an individual client may be within reason.

The more important issue of advocacy is apt to be a more ongoing concern, however. Many multi-impaired blind and deaf-blind individuals will have a regular and consistent need for advocacy services. These services can include the monitoring and evaluating of a client living arrangement, vocational placement, individual service plan, financial status, and other variables. Advocacy in most cases should be made available to clients from individuals who are not directly responsible for delivering services to the client. This inherent conflict of interest can only be avoided if a client's friend,

family member, or other third party source is identified as the primary advocate. Ideally, the advocate should be somewhat knowledgeable about the area of client rights and various legislative and/or legal issues. However, this may not always be possible. An advocate who truly has the client's best interest as a primary concern can become knowledgeable and familiar with those processes and the advocate can be an effective and on-going resource for the client.

For those individuals administering housing programs in the community, and advocate for each client can be a significant part of the service delivery system they are providing. Services beyond informal advocacy for some multi-impaired blind and deaf-blind clients will be discussed in the next section.

- Volunteer Services - Volunteer Services can be an integral and very necessary set of services for many multi-impaired blind and deaf-blind individuals who are living in the community. Given many of the cost considerations that are inherent with community-based living, the development of a volunteer network by professionals operating programs for clients can be the difference between cost-effective programs and ineffective, unstable services. Volunteers can be trained in many areas and they can provide services to clients such as transportation, food shopping, banking, recreation, and others. Clients themselves in some cases will need to be tranined to effectively use and appreciate volunteer services and it is the responsibility of the direct services staff and clients to assure an on-going continuum of volunteer services to community-based programs.

This section has attempted to define an array of major support services that multi-impaired blind and deaf-blind individuals will need if they are to be effectively integrated into the mainstream of a community. Each service has financial, programmatic, and scheduling implications and each service

needs to be analyzed for the specific needs of each client as well as the complexities associated with small and/or large groups who are living in a congregate living arrangement. The importance of researching, implementing, and following through on these support services will obviously be critical if community-based living and working options for clients are to continue to function in a reasonable and secure manner.

LONG-TERM OR LIFE-LONG CARE SYSTEMS

FINANCIAL CONCERNS/ESTATE AND TRUST PLANNING/FEDERAL AND STATE LEGISLATION AND FUNDING ISSUES

As the issues of housing and vocational options have been outlined and as the issues relating to support services in the community have been described, it is imperative that we now analyze the issues of Long-Term or Life-Long Care Needs, Financial Concerns, Estate and Trust Planning, and Federal and State Legislation and Funding Issues.

The services that many multi-impaired blind and deaf-blind individuals will require will necessitate long term, expensive services if we intend to provide adequate and well supervised housing and vocational options as well as leisure time and recreation services.

The most significant problem facing multi-impaired blind and deaf-blind individuals is an inadequate array of entitlement programs to adequately finance the costs associated with structured or semi-structured living and vocational training programs in the Community. The basic S.S.I. entitlement with related Medicaid coverage does not adequately meet the costs associated with residence staff salaries, fringe benefits, rent, utilities, food, and personal needs costs.

As professionals we have the responsibility to advocate and help design cost-effective and reasonable community-based services for the individuals we serve, and we have the responsibility to lobby and become politically active in assuring that private resources will be developed along with Federal and State legislation.

For those whose funtional ability require our attention, concern, and commitment over the full course of their life span, we must meet the challenges of life-long planning. As our society becomes committed to

de-institutionalization and as our levels of consciousness in the areas of living, vocational, and support services options for individuals becomes more sophisticated, it is necessary for us to develop with funding agencies, consumers, and parents a comprehensive and secure system of life-long care options.

One area that needs considerable exploration on a private level is the emerging area of Estate and Trust Planning. Estate and trust planning is a relatively new concept and, as professionals, we need to familiarize ourselves with complicated legal, fiscal, and economic issues related to the development of effective planning strategies to obtain security, peace of mind, and consistent and reasonable life-long care systems for multi-impaired individuals.

For beneficiaries, financial assistance can come from families, friends, and private organizations. In the book "Alternatives" by L. Mark Russell, there are six (6) major issues or questions that parents often raise regarding their handicapped son or daughter:

"- Does my child need a legal guardian?
- Can I control who will be the guardian of my child when I die?
- How can I give money to my disabled child without jeopardizing eligibility for government benefits and exposing this money to collection by the government?
- Am I taking advantage of all the possible medical deductions and credits that I am entitled to receive?
- Will the proceeds from my life insurance policy actually reduce my child's financial resources? If so, how can I correct that problem?
- What is the easiest way of obtaining medical insurance for my handicapped child? What provisions should I look for in the policy?

Mr. Russell goes on to state that:

" 'Estate planning is not an activity for only the wealthy.

> Parents must plan their estates, regardless of size, to secure the continual care and independence of the disabled child. Estate Planning should be broadly viewed to include both financial and personal planning. All parents need to consider whether or not a guardian is needed for their mentally disabled child now or after their deaths. Families with limited financial resources must learn to maximize government benefits and stretch the value of their money by taking advantage of the available medical tax deductions and credits, by choosing the most effective medical insurance for the disabled person, by getting the most out of their life insurance, by knowing why trusts can be so practical for families who rely on government benefits, by investing prudently, and so forth."

There are many different alternatives available to parents and each family situation is unique. It is therefore, critical that parents consult with a competent and knowledgeable attorney in the area of disability legislation in order to design a realistic and practical plan for their disabled family member.

For multi-impaired blind and deaf-blind individuals whose families have the resources and the capacity to plan a financial future for them it is conceivable that a combination of resources will help pay or will, in fact, cover the long-term costs associated with comprehensive community-based services. Various trusts or guardianship structures can be arranged, and legal advice regarding their implication should be analyzed before closure is realized. Whatever form of arrangement is made, the primary purpose should be to protect the interest of the beneficiary, while at the same time protecting the handicapped individual to entitlement benefits.

Estate and financial planning for the disabled individual requires special considerations not ordinarily required by conventional planning.

Various planning alternatives can include but are not necessarily limited to:

- Conservatorship
- Guardianship
- Limited Guardianship
- Informal Care Arrangements
- Gifts Outright
- Trust Funds
- Insurances
- Joint Bank Accounts
- Restricted Bank Accounts
- Power of Attorney
- Representative Payee

As we become more familiar and more knowledgeable in these areas we have the responsibility to advocate and advise parents to seek professional and competent legal advice, in conjunction with their insurance agents, so that the most effective economic plan can be designed for the disabled individual. Preliminary considerations must include an understanding of various disability classifications and the emerging, yet changing legal rights domain.

Within the planning process of estates and trusts an evaluation of the disabled individual, an analysis of resources which will be available, and the objectives of the parents must all be taken into consideration. To assure the provision of adequate and secure financial support, a responsible financial trustee should be considered in order to secure an advocacy role for the multi-impaired blind or deaf-blind individual, and at the same time, provide expertise in the management of the trust fund.

There are many operational considerations which need attention in relation to life-long care sytems, including the roles of residence and support staff, admission criteria, and support services within the community. Specific and comprehensive medical services, as well as advocacy and legal expertise, need to be accessible and available.

Careful planning with other human service agencies, private foundations, and parents will be critical if humanizing and comfortable living options

with appropriate vocational, recreational, and social activities are to be realized. This is a broader definition of the role of the educator or rehabilitation worker than previously defined, but its importance to the particular individuals we serve speaks for itself.

Aside from the private resources just mentioned, it is also fair to say that many multi-impaired blind and deaf-blind individuals will have limited, if any, resources beyond government entitlement or government eligible funding programs. For these individuals the future remains a question, and there continues to be inadequate Federal and State monies available to pay for all clients when their combined housing, vocational, and support service costs exceed their S.S.I. income, limited work income, or other resources. The issue of funding is a complex issue to define. One needs to look at each client on a individual basis, analyze his or her present financial status and compare their resources against their individual costs in a semi-supervised apartment, staffed apartment, community residence, or other living arrangement. Then the client's personnel needs and related costs as well as support service costs must be added and compared against their monthly income.

Individuals living in an Intermediate Care Facility for the Mentally Retarded - Type B would be eligible for medicaid and his or her housing and day program costs would be covered by the I.C.F budget. This is a fairly all-inclusive program so that most, if not all, of their needs would be covered through this funding vehicle.

There are a few pieces of legislation that have recently appeared, and they hold some potential for multi-impaired blind and deaf-blind individuals as it relates to their living costs in the community.

In Massachusetts, Chapter 688 of the Acts of 1983 is intended to provide continued services to severely disabled young adults whose graduation or age (attaining age 22) no longer entitles them to special education services. This applies only to individuals who loose their right to special

education on or after the effective date of the Act (3/22/84). A considerable amount of work is needed to adequately fund the legislation and to ensure proper implementation. However, for the large number of multi-impaired blind and deaf-blind individuals who will be turning twenty-two after 3/22/84 it offers some hope.

On a National level the following efforts may help address the financial issues just mentioned:

- The Community and Family Living Amendments of 1983, if passed, would gradually shift the federal share of medicaid funds from institutions to community-based, integrated settings. Most services funded by this Act would have to be provided in family scale living arrangements, and an Individual Service Plan (I.S.P.) would be required for each client, and it would pay for a number of support services which the client accessed in the community.
- Section 2176 of the 1981 Reconciliation Act is presently being explored by the Massachusetts Department of Mental Health to determine its applicability to permit the State to finance through the Federal-State Medicaid Program, noninstitutional services for disabled persons who would otherwise require care in a Title XIX - certified institution. This appears to have potential in assisting to a transition to more cost-effective networks of community providers.
- Public Law 98-199 emphasizes the development of Transitional Services for handicapped youth. An important part of the Law is that transition implies cooperation on the part of service providers in identifying service alternatives and making sure that the "system" works for the benefit of handicapped youth rather than proliferating gaps between education and rehabilitation.

There may be other efforts in various states to help address the significant issue of funding, and it is our responsibility to work closely with clients, families, advocates, human service agencies, and the private sector in developing a wider array of financial, legislative, and legal

options and opportunities for multi-imapired blind and deaf-blind individuals and their families.

SUMMARY AND RECOMMENDATIONS

It is important to be constantly assessing ourselves and the programs we are administering. It is important to focus our attention on staff development and professional development issues related to present strategies and future needs. In addition to staff development issues, however, we need to be looking at more global issues as they relate to services for the students and clients we serve.

We need to be more conscious and more responsive to:

- The development of state-of-the-art and resourceful support and technical assistance procedures to insure comprehensive operational and management systems within educational and rehabilitational agencies.
- The development of leadership training and supervisory and administrative training focusing on the structuring of interdisciplinary team services and community-based services.
- The development of research, long-term planning strategies, and policies and procedures which will expand and reinforce the process of integration within community-based settings.
- The development of advocacy and legal services for multi-impaired blind and deaf-blind individuals and their families.
- The development of relevent and innovative curricula which is geared to effectively integrate and allow multi-impaired blind and deaf-blind individuals to function independently or semi-independently in

future living and vocational/work options within various communities.

- The development of a comprehensive and tangible in-service training program for all clinical, teaching and residence staff with an emphasis on behavior management techniques, creating inter-disciplinary teams in education and rehabilitation programs, vocational program options, sex education, family and life training, community-based housing services, and intensive medical in-service training with an emphasis on first aid training, CPR training, and adaptive techniques for multi-impaired clients in need of physical therapy and occupational therapy.

- The development of education and rehabilitation programs which focus on true accountability by assuring that each student or client, upon termination of his or her program has been adequately prepared to meet the demands expected of one who lives and works in various community options.

- The development of comprehensive and reality-based programs for the more multi-impaired. Services need to focus on appropriate training programs which are geared towards structured or semi-structured living and work options in the community. Funding availability of community resources, and long-term program commitments will be needed in order to insure that this population has the opportunity to receive services which will be much longer in duration than education, special education, or rehabilitation agencies are accustomed to providing.

- The development of attitudes and programs which will help in the planning and implementation of life-long care systems which will provide appropriate and respectable options for a multi-impaired population.

- And finally, the development of responsible and well educated interdisciplinary teams who can assess, design, and follow through on individual education and rehabilitation plans which are truly individual for each student and client we serve.

Accountability or the concept of being answerable is our professional responsibility, and the multi-impaired blind, visually impaired, and deaf-blind individuals we serve depend very heavily on us to interpret and follow through on program design and implementation. How well we organize and design services and to what extent we become involved with living options and vocational options in the community and life-long care systems will determine our definitions and our commitment to the concept of accountability. In essence, it will determine the extent of our commitment to the multi-impaired individuals we serve.

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